

RESOURCE DOCUMENT

MEASURING ACCESSIBLE MEDICAL INSTRUMENTATION: ANNOTATED BIBLIOGRAPHY

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Table of Contents

I. Purpose of Bibliography	4
II. Background	4
III. Need to measure accessibility of medical equipment.....	5
a. McClain, L., Medrano, D., Marcum, M., and Schukar, J. (2000). A qualitative assessment of wheelchair users' experience with ADA compliance, physical barriers, and secondary health conditions. Topics in Spinal Cord Injury Rehabilitation, 6 (1), 99-118	5
b. Rimmer, J. H., Riley, B., Wang, E., Rauworth, A., Jurkowski, J. (2004). Physical activity participation among persons with disabilities: Barriers and facilitators. American Journal of Preventive Medicine, 26(5), 419-425	6
c. Nary, D. E., Froehlich, A.K., and White, G.W. (2000). Accessibility of fitness facilities for persons with physical disabilities using wheelchairs. Topics in Spinal Cord Injury Rehabilitation, 6(1). 87-98	6
d. Grabois, E. W., Nosek, M. A., Rossi, D. (1999). Accessibility of primary care physicians' offices for people with disabilities: An analysis of compliance with the Americans with disabilities act. Archives of Family Medicine, 8, 44-51.....	7
e. Sanchez, J., Byfield, G., Brown, T. T., LaFavor, K., Murphy, D., Laud, P. (2000). Percieved accessibility versus actual physical accessibility of healthcare facilities. Rehabilitation Nursing, 25(1), 6-9	8
f. Reniscow, K. A, Schorow, M. , Bloom, H.G., and Massad, R. (1989). Obstacles to family practitioners' use of screening tests: Determinants of practice. Preventive Medicine, 18, 101-1129	
g. Young, M. E.; Grabois, E. (2001). Managed care experiences of people with disabilities. Journal of Rehabilitation, 67(3), 13-20	10
h. Batavia, A. I., Hammer, G. S. (1990). Toward the development of consumer-based criteria for the evaluation of assistive devices. Journal of ion Research and Development, 27(4), 425-437	11
i. Veltman, A., Stewart, D. E., Tardiff, G. S., Branigan, M. (2001). Perception of primary healthcare services among people with physical disabilities. Part I: Access Issues. Medscape General Medicine, 3(2)	12
j. Nosek, M. A. (2000). Overcoming the odds: The health of women with physical disabilities in the United States. Archives of Physical Medicine and Rehabilitation, 81, 135-138	12
k. Sullivan, S.G., Glasson, E. J., Hussain, R., Petterson, B. A., Slack-Smith, L. M., Montgomery, P. D., and Bittles, A. H. (2003). Breast cancer and the uptake and of mammography screening services by women with intellectual services. Preventive Medicine, 37, 507-512.....	13
l. Coyle, C. P., Santiago, M. C. (2002). Healthcare utilization among women with physical disabilities. Medscape General Medicine, 4(3).....	14
m. Nosek, M. A., Howland, C. A. (1997). Breast and cervical cancer screening among women with physical disabilities. Archives of Physical Medicine and Rehabilitation, 78, s39-s4	15
n. Becker, H., Stuifbergen, A., Tinkle, M. (1997). Reproductive healthcare experiences of women with physical disabilities: A qualitative study. Archives and Physical Medicine and Rehabilitation, 78, s26-s33	16

o.	Nosek, M. A., Young, M. E., Rintala, D. H., Howland, C. A., Foley, C. C., and Bennett, J. L. (1995). Barriers to reproductive health maintenance among women with physical disabilities. <i>Journal of Women's Health</i> , 4(5), 505-518.....	16
p.	Cheng, E., Myers, L., Wolf, S., Shatin, D., Cui, X. P., Ellison, G., Belin, T., and Vickery, B. (2001). Mobility impairments and the use of preventive services in women with multiple sclerosis: Observational studies. <i>British Medical Journal</i> , 323, 968-969.....	17
q.	Whiteneck, G. G., Harrison-Felix, C. L., Mellick, D. C., Brooks, C. A., Charlifue, S. B., Gerhart, K. A. (2004). Quantifying environmental factors: A measure of physical, attitudinal, service, productivity, and policy barriers. <i>Archives of Physical Medicine and Rehabilitation</i> , 85, 1324-1335.....	18
<i>IV.</i>	<i>Conclusion</i>	<i>21</i>
<i>V.</i>	<i>Future Research</i>	<i>21</i>
<i>VI.</i>	<i>References</i>	<i>23</i>

Measuring Accessible Medical Instrumentation: Annotated Bibliography

I. Purpose of Bibliography

The accessibility of medical instruments is a new field of concern and study. An important implication of the inability of people with disabilities to use medical devices due to inadvertent design directly contradicts the intent of the ADA. Furthermore, inaccessible design of medical equipment can be life threatening. The purpose of this annotated bibliography is to provide a historical resource about literature available in this topic to support interested parties.

II. Background

Key advances in health care technology in the 1930's and the 1940's dramatically increased the survival rate of individuals with severe disabilities (Gans, Mann, and Becker, 1993). Advances included the development of antibiotics, acute trauma care systems, respiratory support systems and ultimately cardiopulmonary resuscitation methods and systems. According to the U. S. Census Bureau, more than 20% of the general population suffers from some form of disability which could be mobility/dexterity disabilities; cognitive disabilities; sensory or language disabilities; and a variety of other conditions (Wilcox, 2003). In addition, the disability rates for women have shown an increase (Kaye, LaPlante, Carlson, & Wenger, 1996).. These conditions lead to increased requirement for health care facilities and services to provide specialty services or routine medical examinations for people with disabilities. There is also an increasing trend to minimize patient care in the hospital, thus entailing the migration of medical devices from medical facilities to patient's homes (Wilcox, 2003).

In both circumstances there is a need for the manufacture and utilization of accessible medical instruments to facilitate access for individuals with a variety of disabilities. Accessible medical instruments includes diagnostic equipment including monitoring devices (thermometer) or imaging devices (MRI); procedural equipment such as (furniture/fixtures); therapeutic equipment for either drug therapy or physical therapy or assistive technologies (wheelchairs, hearing aids, etc) (RERC-AMI, 2003).

Little research has been conducted to better understand the difficulties individuals face in accessing medical devices. Furthermore, research focusing on accessibility limits itself to examination tables, health insurance, and architectural barriers. The published literature is limited to people with physical disabilities or women with reproductive health care needs. However, people with cognitive and behavioral impairments will face problems which are very different from those faced by an individual with a physical impairment. Thus, there is a need to assess the access limitations posed by medical devices for people with a wider variety of disabilities.

III. Need to measure accessibility of medical equipment

There has been a fair amount of research conducted in the area of barriers to health care services for people with disabilities; however, little focus had been placed on the accessibility barriers that medical instrumentation and equipment can present. Research related to this area has tried to identify various access difficulties that people with disabilities face which may be person centered or environment centered. A number of surveys and questionnaires have been developed for this purpose.

- a. **McClain, L., Medrano, D., Marcum, M., and Schukar, J. (2000). A qualitative assessment of wheelchair users' experience with ADA compliance, physical barriers, and secondary health conditions. *Topics in Spinal Cord Injury Rehabilitation*, 6 (1), 99-118**

Summary of Article: A qualitative study was carried out by McClain, Medrano, Marcum and Schukar (2000) to assess the impact of the physical and attitudinal barriers upon the ability of wheelchair users to access community goods and services; the impact of the physical environment upon roles in families and community; and issues of isolation and secondary health conditions relative. They used the naturalistic inquiry process of Lincoln and Guba due of its ability to evoke personal perspectives and the Craig Hospital Inventory of Environmental Factors (CHIEF), which is a structured interview. Five participants, who lived in the community, were wheelchair users, and had no other health problems were recruited.

Summary of results of study: Results of the assessment indicated architectural barriers such as like doors, ramps, stores, bathrooms; barriers to medical settings such as doors to the offices, insurance and inaccessible chairs in dental settings; attitudinal barriers; and lastly inability to use exercise equipment due to absence of adaptations acted as barriers to healthcare services. Due to all these barriers people with disabilities experienced frustration, isolation and a sense of settling for less.

Measurement: The researchers used a qualitative method known as 'Naturalistic Inquiry/Constructivism' approach by Lincoln and Guba for this study. The data was collected over a period of fifteen months. Two semi structured interviews were created for this study. The first interview focused on the participants' perceptions of physical barriers and the impact of ADA upon their (1) ability to access community goods and services, (2) their roles in family and community, (3) issues of isolation and secondary health conditions The second interview was based on themes that emerged from the first set of interviews. The final interview had two phases. First there were follow-up questions from the set of themes that emerged from the second set of interviews. Second, the Craig Hospital Inventory of Environmental Factors (CHIEF), a structured interview, was administered. In this assessment salient dimensions of the person's environment are self-evaluated with attention to whether they impede or facilitate a person's participation in the community. The scale includes accessibility accommodation, resource availability, and social support issues. The CHIEF was comprised of 25 item pairs that address the frequency of a problem (daily, weekly, monthly, less than monthly, never) and the

severity of a problem (big problem, little problem). The item pairs were not listed in the article.

- b. **Rimmer, J. H., Riley, B., Wang, E., Rauworth, A., Jurkowski, J. (2004). Physical activity participation among persons with disabilities: Barriers and facilitators. American Journal of Preventive Medicine, 26(5), 419-425**

Summary of Article: People with disabilities experience a wide range of secondary health issues due to their sedentary lifestyles. Regular physical activity can help alleviate these problems as well as reducing symptoms of anxiety and depression (Ross and Hayes, 1988). Exercise is recommended as a preventive measure for such conditions; however exercise equipment is not made accessible for people with disabilities. A study was conducted by Rimmer, Riley, Wang, Rauworth and Jurkowski (2004); to identify various barriers and facilitators associated with participation in fitness and recreation programs or facilities as perceived by people with disabilities and professionals who have direct or indirect influence on accessibility of physical activity and recreation facilities and programs. Focus groups of four to six individuals each were conducted in ten regions across the United States with four types of participants: consumers with disabilities, architects, fitness and recreation professionals, and city planners. The focus groups were instructed to address access issues related to four types of fitness /recreation venues: (1) fitness centers, (2) swimming pools, (3) parks, and (4) trails. Notes were taken during sessions. Sessions were tape recorded and notes were taken of identified barriers and facilitators to access.

Summary of results of study: The barriers and facilitators related to access and participation in physical activity reported by people with disabilities were related to the built and natural environment; cost; equipment; guidelines, codes, laws; information; emotional or psychological; knowledge, education and training; perceptions and attitudes; policies and procedures and resource availability. Specific barriers identified with respect to equipment were not enough space between equipment for wheelchair access, poor equipment maintenance, and lack of adaptive and accessible equipment. Conclusions reached were that the degree of participation in physical activity among people with disabilities is affected by a multifactorial set of barriers and facilitators that are unique to this population.

Measurement: Focus groups were asked to address access issues as listed above. Notes and tape recordings of sessions were the primary means of gathering data.

- c. **Nary, D. E., Froehlich, A.K., and White, G.W. (2000). Accessibility of fitness facilities for persons with physical disabilities using wheelchairs. Topics in Spinal Cord Injury Rehabilitation, 6(1). 87-98**

Summary of Article: Nary, Froehlich, and White (2000) conducted a study to evaluate the degree of ADA compliance of fitness facilities. Eight fitness facilities were recruited as participants for this study in Topeka, Kansas. Researchers visited the fitness facilities and collected data.

Summary of results of the study: It was found that only one facility had a completely accessible path of travel throughout the interior, two facilities featured completely accessible paths between and around fitness equipment, one facility had a pool that was fully accessible and none of the facilities had adaptive fitness equipment like an arm ergometer. Thus, it was concluded that fitness facilities need to enhance access so that wheelchair users can use them to increase their physical activity and overall health.

Measurement: The researchers developed instrument checklist based on the pertinent sections Americans with Disabilities Act Accessibility Guidelines (ADAAG) for use in this study. An 83-item wheelchair-accessibility checklist was adapted from a checklist originally developed by McLain et al. and was adapted for fitness facilities based on a survey of fitness facilities conducted by Figoni et al. It covered the ten items listed above and for each of these categories, between 4 to 12 specific items were measured using ADAAG standards. The survey focused on portions of ADAAG that addressed access for people with mobility impairments. The instrument covered ten areas of fitness facilities including parking, ramps, exterior entrances/doors, interior paths of travel, elevators, restrooms and locker rooms, telephones, drinking fountains, customer desk service and access in and around exercise equipment. An adapted digital fish scale was used to measure the force required to open doors and a steel tape measure was used to measure various widths required by ADAAG. Six additional questions were asked about items not addressed by ADAAG, including pool access, adaptive equipment, staff training, adaptive programming, pro-rating of membership fees based on accessibility, and visits at no charge to assess accessibility for individuals with disabilities.

- d. **Grabois, E. W., Nosek, M. A., Rossi, D. (1999). Accessibility of primary care physicians' offices for people with disabilities: An analysis of compliance with the Americans with disabilities act. Archives of Family Medicine, 8, 44-51.**

Summary of Article: People with disabilities frequently require medical care, however, medical facilities are not always accessible to people with disabilities. A study was conducted by Grabois, Nosek and Rossi (1999) to determine if primary care physicians are in compliance with the ADA and to what extent offices of primary care physicians are usable for persons with disabilities. A questionnaire was sent out to 220 physicians and included the following specialties: general practitioners, family practitioners, internists, and obstetrician-gynecologists. Out of these, 62 responded to the questionnaire.

Summary of results of study: Results of the questionnaires showed that 12 of the physicians examined their patients in wheelchairs and 21 sometimes examined their patients in wheelchairs. Twenty four respondents used or purchased an adjustable height examination table and 8 had padded examination tables the height of the wheelchairs. Only one physician had a platform or sitting scale. A substantial portion of primary care physicians' offices not in compliance with ADA guidelines and some informational tools will be required to inform physicians about the nondiscriminatory requirements of the statute.

Measurement: The main outcome measure was the fifteen page questionnaire with 57 items and 136 variables which were created based on examples found in the ADA statute, Code of Federal Regulations, and published articles. The questions were designed to measure the physicians' compliance with ADA. The researchers did not use any standardized measurement tool in the questionnaire. In the questionnaire the definition of a person with a disability was drawn from the ADA statute. Examples given to physicians of conditions and diseases of patients protected by the ADA included seeing, hearing, learning, or orthopedic impairments; cerebral palsy; muscular dystrophy; multiple sclerosis; cancer; heart disease; diabetes; tuberculosis; spinal cord or brain injury; past history of alcoholism or other drug addiction; some current alcoholism; and illness related to human immunodeficiency virus infection and acquired immunodeficiency syndrome.

The first group of questions included demographics. The second group of questions was designed to show whether the physicians were complying with the general prohibitions of Title III of the ADA. Examples of questions asked were 'In the last 12 months, has anyone with a disability not been able to receive services in your practice for the following reasons: (a) you or your staff was not familiar with the disability of the patient; (b) you were unable to use your equipment with the patient because it was not accessible (c) patient was difficult to treat or handle etc.' These questions were also designed to show whether the physicians were providing goods or services to their patients in integrated settings.

The third group included questions to determine whether physicians were complying with the specific prohibitions under Title III, including setting up eligibility criteria that tend to screen out patients with disabilities and failing to make modifications in policies, practices, and procedures and the last group included questions to find whether physicians were making an effort to remove architectural and communication barriers that were structural in nature. They were also asked questions to obtain information on some of the features of the ideal physicians' office for patients with disabilities.

The questions were designed to assess if the physicians were complying with the general prohibitions of Title III of the ADA and asked questions related to physicians' exposure to people with disabilities and their competence in dealing with them. Questions were also geared towards assessing accessibility of physicians' office and equipment for people with disabilities.

- e. **Sanchez, J., Byfield, G., Brown, T. T., LaFavor, K., Murphy, D., Laud, P. (2000). Perceived accessibility versus actual physical accessibility of healthcare facilities. *Rehabilitation Nursing*, 25(1), 6-9**

Summary of Article: Sanchez, Byfield, Brown, LaFavor, Murphy and Laud (2000) carried out a study to evaluate how healthcare clinics perceived themselves in regard to accessibility for persons with spinal cord injury (wheelchair accessibility). The subjects for this study were 40 randomly selected; computer generated healthcare clinics from a Midwestern city. The clinics included medical and integrated care facilities.

Summary of results of study: Of the 40 sites contacted, all identified their facilities as wheelchair accessible. Eighty two percent of the sites would require that the person be physically transferred which could result in injury for the clinician. The information given by the manager or facility representative was compared with results of the site survey. Thirty eight percent sites reported that examination tables could be lowered while only 17.5% had such a table. One site did not know. Conclusions that were drawn were that although 100% of the clinics participating reported themselves as wheelchair accessible, the number that actually met the guidelines was variable. In general although a wheelchair could enter the healthcare building, examination room and bathroom; a majority of sites didn't have an examination table that could be lowered to wheelchair level, most clinics had limited experience working with persons with spinal cord injury and very few knew what to do if a client had a medical emergency due to autonomic dysreflexia. "Perceived accessibility" appeared to be solely based on basic physical access, without consideration of the real needs and issues of the persons with mobility impairments.

Measurement: A phone assessment with the managers of the facilities was conducted during which he/she completed a brief oral questionnaire to ascertain the perception of the clinic's accessibility. Some examples of questions asked are: Does the site consider itself to be wheelchair accessible? Does the site have a wheelchair-accessible bathroom, an examination table that can be lowered to wheelchair level, and handicapped parking available? Has the staff ever treated anyone with spinal cord injury? Has the staff any experience with wheelchair transfers? Etc.

Then an onsite survey addressed factors considered essential to access in a healthcare facility based on recommendations of the Adaptive Environments Center's Checklist for Existing Facilities. Six features of the clinic which were evaluated were parking lots, entrance to the building, entrance to the clinic, lobby, examination room and bathroom.

- f. **Renisow, K. A, Schorow, M. , Bloom, H.G., and Massad, R. (1989). Obstacles to family practitioners' use of screening tests: Determinants of practice. Preventive Medicine, 18, 101-112**

Summary of Article: There has always been a question regarding obstacles that family practitioners face with respect to using screening tests. To answer this question, a survey of periodic health screening practices was carried out by Resnicow, Schorow, Bloom and Massad (1989); where physicians were asked to check the nine listed obstacles that most affected their use of the listed screening practices. The survey was sent to 630 physicians from the Society of Teachers of Family Medicine (STFM) and the American Academy of Family physicians (AAFP), but only 275 responded

Summary of results of study: The most commonly reported obstacle was cost to the patient. Lack of facilities or equipment was listed as an obstacle for four tests which were hearing evaluation (30%), tonometry (17%), mammography (15%) and sigmoidoscopy (12%). In

summary, the study indicated that obstacles can be trichotomized as physician-, test-, or patient oriented. Patient oriented obstacles, such as cost and inconvenience were less likely to affect physicians' practices than factors that impede test performance such as equipment or physicians' beliefs about the efficacy of a test.

Measurement: A 22 page survey instrument was developed to assess physicians' use of individual screening tests. The questionnaire covered a broad spectrum of diseases and tests considered for inclusion in a periodic health examination. The obstacles were selected based on a review of the relevant literature as well as interviews with clinicians. The nine obstacles listed were cost to the patient, patient reluctance and refusal, inconvenience or discomfort to the patient, lack of facilities and equipment, tests require too much time, the literature recommends not to use the test, risk to the patient, insufficient training and too high a rate of false positives and negatives. A grid was developed with nine potential obstacles on the vertical axis and nine screening tests on the horizontal axis. The content and format of the survey were reviewed by several researchers in the area and were then field-tested with primary care physicians. The split-half reliability coefficient of the instrument was 0.93

- g. **Young, M. E.; Grabois, E. (2001). Managed care experiences of people with disabilities. Journal of Rehabilitation, 67(3), 13-20**

Summary of Article: Young and Grabois (2001) carried out a study to describe the experiences of individuals with disabilities in managed care organizations. Sixteen individuals who were at least 18 years of age with selected disabilities who received care in a health maintenance organization or a preferred provider organization participated.

Summary of results of study: Results showed that some participants reported problems in getting a mammogram and with physical therapy services like absence of an assistive lift and physical therapy pool. Seven participants reported dissatisfaction with health care providers due to inaccessible equipment. Problems were with getting onto an examination table because they were not adjustable and getting an X-ray because they were in wheelchairs. Some participants reported problems with getting a mammogram or eye examination that was effective due to inability to get into the right position for the equipment to work properly. Some never knew their weight because their physicians didn't have platform or sitting scales. People with disabilities have complex health care needs, frequent medical complications and are highly vulnerable medically. Participants reported both benefits (cost efficiency, total package of health care services, preventive health care tests) as well as problems (inaccessible equipment, brief office visits, payment issues) with reference to health care services.

Measurement: The investigators designed a non standardized questionnaire which included both a list of general topics to be discussed and some open ended questions to prompt the interviewees. There were some major topics addressed in this study which were as follows: Background material on the participants, different types of providers participants used, services included by MCO's, satisfaction level of the participants, major practices of MCO's both beneficial and problematic and lastly the medical and nonmedical

problems of the participants. The questionnaire included a list of both general topics to be discussed with the interviewees and some open ended questions to prompt the interviewees. The interviews were semi-structured and conversational. The participants reported getting care from a wide range of providers like physicians, specialists, nurses, nurse practitioners, physician assistants and physical therapists. Services included were mammograms, pap smears and diet information and services.

- h. Batavia, A. I., Hammer, G. S. (1990). Toward the development of consumer-based criteria for the evaluation of assistive devices. Journal of Consumer Research and Development, 27(4), 425-437**

Summary of Article: Batavia and Hammer (1990) conducted a study to constitute an initial step toward the development of design, engineering, and selection criteria based on the specific concerns of the consumers. This study applied a small focus group process to identify and prioritize factors used by long term users of assistive technology in assessing their devices. Two panels of long term users of assistive technology were selected—a panel of consumer experts with mobility impairments and a panel of consumer experts with sensory impairments—on the basis of three criteria: had to have a physical disability (i.e. either mobility impairment or a sensory impairment); be a long term user (at least 5 years) of one or more assistive technology for persons with his/her disability; and have well developed analytical and communicative skills necessary to identify, prioritize, and convey his/her factors for assessing technology.

Summary of results of article: The findings of the assessment indicated that effectiveness, affordability, operability and dependability are on average the four most important factors for all technologies assessed. The ranking of other factors depended largely on the specific technology being assessed. A consensus emerged among the sensory panel that, to the extent that a device is testable in the general market, the market provides the best means by which to evaluate the device. However, the market test is not available for many products needed by persons with disabilities because many devices for disabled persons are not purchased in the general market such as devices specific to certain disabilities that occur infrequently in the general populations. Therefore for those assistive technologies that are not adequately tested in the market, normative evaluation criteria are needed to guide selection, design and manufacturing processes.

Measurement: A modified form of Delphi method using focus groups was utilized. Prior to convening the panels, the investigators developed and defined the following 12 factors: Affordability, Consumer Repairability, Dependability, Durability, Ease of Assembly, Ease of Maintenance, Learnability, Operability, Personal Acceptability, Physical Comfort, Physical Security, and Supplier Repairability. Panel members were asked to identify the factors they use in assessing their own technologies. They were then asked to compare their factors with those developed by the principal investigators to determine whether additional factors should be added to the initial list. The Mobility Panel added three factors: Compatibility, Effectiveness, and Flexibility. The Sensory Panel added two additional factors: Portability and Securability. The list of factors agreed upon by the group was randomized, and panel members were asked to indicate their priorities for the

factors in order of importance. The outcomes were measured in terms of development of a comprehensive consumer based criteria for the evaluation of assistive devices in order of priority for the consumer.

- i. **Veltman, A., Stewart, D. E., Tardiff, G. S., Branigan, M. (2001). Perception of primary healthcare services among people with physical disabilities. Part I: Access Issues. Medscape General Medicine, 3(2)**

Summary of Article: In addition to assessing healthcare providers' perception of access to medical facilities, it is also important to assess the perception of accessibility of people with disabilities to health care facilities. Such a study was conducted by Veltman, Stewart, Tardif and Branigan (2001) to examine the extent of access to and satisfaction with primary healthcare services for people with disabilities. An anonymous self report questionnaire regarding access to and perceived quality of primary healthcare was mailed to a convenience sample of 1026 members of several disability organizations as well as persons discharged from a rehabilitation hospital within the past two years.

Summary of results of study: From the analysis it was noted that participants reported a wide range of physical access barriers including difficulty accessing their family doctor's offices 32% of the time and equipment 38% of the time. Although people who experienced more difficulties may have been more likely to respond to the survey, a significant proportion of people with physical disabilities felt they were experiencing difficulty accessing adequate and appropriate primary healthcare services.

Measurement: The questionnaire was developed based on a literature review, interviews with key medical and consumer informants, and the Short Form-36 Health Survey from the Medical Outcome study. For the 201 returned surveys, the authors evaluated the perceived extent of access to primary healthcare services as well as the level of satisfaction with the quality of these services. Descriptive analysis (frequencies, means, and standard deviations) of categorical and continuous variables were conducted.

- j. **Nosek, M. A. (2000). Overcoming the odds: The health of women with physical disabilities in the United States. Archives of Physical Medicine and Rehabilitation, 81, 135-138**

Summary of Article: A lot of research has shown that women face additional access issues especially related to reproductive health. To assess the barriers to health care that women with physical disabilities face a large amount of data was collected by Margaret Nosek (2000) from four sources: a national study conducted by the Center for Research on Women with Disabilities that involved more than 500 women with physical disabilities and an equal number of non-disabled friends; an analysis of the 1994 and 1995 census data which included approximately 11,500 women aged 18 years and above; a recently compiled chart book on women with disabilities by Lita Jans and Susan Stottard; and the results of the first meeting with about two dozen authoritative women with disabilities and researchers in this area convened by the Center for Disease Control and Prevention in 1997.

Summary of results of article: Results of all this data showed that women with physical disabilities faced a wide range of problems with regard to health care. Pelvic exams and mammograms were not undertaken due to inaccessible examination tables or difficulty with getting into the required position. Young women with more severe disabilities have the most difficulty obtaining mental health care, dental care, prescription medicine and eye glasses. Reasons cited were inadequate finances, health insurance, transportation, lack of attendant services and lack of instruments and equipment that were accessible.

- k. **Sullivan, S.G., Glasson, E. J., Hussain, R., Petterson, B. A., Slack-Smith, L. M., Montgomery, P. D., and Bittles, A. H. (2003). Breast cancer and the uptake and of mammography screening services by women with intellectual services. Preventive Medicine, 37, 507-512**

Summary of Article: High quality gynecologic care is widely recognized as essential to health maintenance for all women. However women with disabilities often have poor access to health care services. This includes women with physical as well as intellectual disabilities. A study was conducted by Sullivan, Glasson, Hussain, Petterson, Slack-Smith, Montgomery and Bittles (2003) to assess the prevalence and effects of breast cancer in women with intellectual disabilities using a community based sample, and then to evaluate their level of uptake of mammographic screening services. Subject for this study were identified through the Disability Services Commission of Western Australia. Inclusion criteria were availability of information on intellectual disability, including a diagnosis or measured level of severity of intellectual disability and aged over 25 years of age. Two thousand three hundred and seventy women were selected as the study sample.

Summary of results of article: Results indicated that of the 2370 women linked with the cancer registry; 11 women with mild-, 4 with moderate-, and 5 with severe intellectual disability had been diagnosed with breast cancer. It showed that women with severe intellectual disability were much less likely to be screened compared to those with mild intellectual disability. The odds of screening were also low for women with cerebral palsy and epilepsy. Many reasons have been proposed for these results such as extent of disability as well as physical disabilities which are not easily accommodated by mammography scanners. In addition women with severe intellectual impairments may experience difficulties in understanding the procedure which can cause anxiety and make it difficult to take an effective X-ray.

Measurement: Two thousand three hundred and seventy women were selected as the study sample. Cases of cancer were identified from the WA Cancer Registry. A subgroup of records linked to the cancer registry were matched with the mammography screening registry maintained by BreastScreen WA, which stores names and contact information used in the mailing list to invite women for a mammogram. Records were chosen if they were shown to be active members of the Disability Services Commission at the time of linkage. Data linked with BreastScreen were evaluated to ascertain the numbers of women who had or had not used the screening services, and the demographic and diagnostic differences between both groups were compared by logistic regression.

Adjusted odd ratios were calculated by a backward stepwise logistic regression method. The model incorporated a range of demographic variables, i.e. age, marital status, area of residence, etc. The health status variables included in the regression model were severity of ID, presence of any physical disability due to cerebral palsy, and history of epilepsy. The statistical analysis were performed using Stata 7 for PC (Statacorp, Texas)

I. Coyle, C. P., Santiago, M. C. (2002). Healthcare utilization among women with physical disabilities. *Medscape General Medicine*, 4(3).

Summary of Article: Coyle and Santiago (2002) carried out a study to assess the healthcare utilization among women with physical disabilities. The target population for this study included 170 women with physical disabilities between the ages of 21 and 65 randomly selected from the current service lists of three major organizations providing services for individuals with disabilities. Seven hundred surveys were mailed; however only 208 completed surveys were returned. From these 38 were not usable because of incomplete data or the respondents being older than the age criterion established for the study.

Summary of results of study: Results showed that almost all (94%) of the 167 women had seen at least one health care provider in the past six months whereas 6% had not visited one in the past six months. In contrast to these findings, only half the women had seen a rehabilitation healthcare provider in the past six months. It has been suggested that the large number of visits to the general healthcare provider can be attributed to the secondary health problems that these women face. Sixty two percent of the women surveyed reported having seen a gynecologist in the past six months, however, 18% reported not having a PAP smear in the past five years, 15% reported not having a breast exam done and 17% who were forty years or older reported not having a mammogram. Reasons for these low rates have been postulated as inaccessible equipment and facilities and transportation.

Measurement: A survey method was used which queried the participants demographics (age, race, educational level, employment status, income etc.). Information was also obtained on respondents (1) primary disabilities, health service usage (type of healthcare provider, frequency of visits to each type of provider in the past 6 months, and types of examinations received in the past 5 years), (2) functional status (how severely disability affected their functioning when performing 14 basic tasks such as transferring from a bed or chair, eating, walking ten steps without rest, dressing, preparing meals, handling money). These 14 items were taken from the Third National Health and Nutrition Examination Survey. Raw data were transformed into a functional status score by computing the average rating across the 14 items. Higher scores on this variable indicated lesser functional independence; (3) and occurrence and severity of secondary conditions. This portion of the survey used a revised version of the questionnaire created by Seekins, Clay, and Raveslout. Respondents were asked to rate the degree to which each secondary condition affected their activity and independence during the past 12 months.

- m. Nosek, M. A., Howland, C. A. (1997). **Breast and cervical cancer screening among women with physical disabilities.** *Archives of Physical Medicine and Rehabilitation*, 78, s39-s4

Summary of Article: Nosek and Howland (1997) reported findings from the National Study of Women with Physical Disabilities about rates of screening for breast and cervical cancer and factors associated with compliance for regular screening with recommended guidelines in a large sample of women with a variety of physical disabilities and a comparison group of women without disabilities. The inclusion criteria for this study were women had to be between the ages of 18 and 65 years; have a physical disability; and, have no cognitive impairments or mental health problems or problems understanding English that would significantly impair the ability to understand and respond to survey items. The findings from this study were used to develop items for this survey. A total of 881 women, 475 with physical disabilities and 406 without physical disabilities completed the written questionnaires. Case comparison study using written survey was used. A national survey of women with disabilities covering reproductive health care as well as dating, marriage, sexual functioning, parenting issues, and developmental issues such as family influences and a women's sense of self as a sexual person was filled out by participants. Each woman was to recruit a non disabled friend to also complete the questionnaire producing a comparison sample. The final version had 311 items containing 1,011 variables.

Summary of results of study: The results were as follows: For Pelvic Examination, of the 843 women (450 with and 393 without disabilities) 7.1% of the women with disabilities received regular pelvic examinations compared to the 72.8% women without disabilities. The most frequently cited reason for women with disabilities not receiving a regular pelvic exam was difficulty getting onto an examination table (37.2%). For Mammograms, of the 881 respondents, 479 were 40 or more years of age, and therefore fall within the guidelines to have had a mammogram. Only 6.75% women reported noncompliance among women with disabilities. Among reasons stated the most frequent was being physically unable to get into required position (34.1%)

In summary, this analysis shows that women with disabilities tend to be less likely than women without disabilities to receive pelvic examinations on a regular basis and those women with more severe functional limitations are significantly less likely to be able to comply with recommended guidelines. However there was no significant difference between women with and without disabilities regardless of severity of functional limitations in receiving mammograms within the past two years. Thus, women with physical disabilities are at a higher risk for delayed diagnosis of cervical and often breast cancer primarily for reasons of environmental, attitudinal and informational barriers.

Measurement: A qualitative interview was conducted with 31 women with disabilities which identified six thematic domains (1) sense of self; (2) relationships (3) barriers including environmental and attitudinal barriers and emotional, physical, and sexual abuse; (4) sexuality information (5) health issues; and (6) sexual functioning. The

findings from this study were used to develop items for the survey. The final version of the questionnaire included 311 items containing 1,011 variables. The researchers did not give any examples of the items, variables or questions used in the survey.

- n. **Becker, H., Stuifbergen, A., Tinkle, M. (1997). Reproductive healthcare experiences of women with physical disabilities: A qualitative study. Archives and Physical Medicine and Rehabilitation, 78, s26-s33**

Summary of Article: Women with physical disabilities are often treated as asexual beings and hence are never asked about contraceptive use or assessed for sexually transmitted diseases. A qualitative study was carried by Becker, Stuifbergen and Tinkle (1997) to assess the reproductive healthcare experiences of women with physical disabilities and to explore ways in which reproductive health care experiences could be improved. Ten women were recruited. Inclusion criteria were women with physical disabilities who were between the ages of 18 and 50 years and could communicate in English.

Summary of results of study: Some of the themes identified were as follows: barriers which included physically inaccessible tables, stirrups, examining instruments, offices, parking lots, transportation to provider or inaccessibility to preferred provider; facilitators were positive attitudes of healthcare provider, physically accessible offices and equipment and knowledge or assertiveness skills of the patient itself; access to birth control which could be hampered due to limited manual dexterity which created problems with using mechanical devices like diaphragms; pregnancy which was discouraged; lack of information about STD's; aging and menopausal issues; and sexuality.

Barriers that were identified can be divided into two major categories: structural barriers related to access or physical accommodation and those concerning relationship with health care providers. The implications for training include directing interventions at enhancing providers understanding of how to work effectively with women with physical disabilities. Efforts should be directed at preparing women with disabilities to be informed about their health care needs. Routine prescriptions for health screening and self care can and should be adapted for women with disabilities.

Measurement: A qualitative interview study was conducted. A semi structured interview was developed to elicit perception about reproductive health care experiences, including access to health care information, access to birth control, experiences with pregnancy or sexually transmitted diseases, barriers to quality services and suggestions for improving reproductive health care services.

- o. **Nosek, M. A., Young, M. E., Rintala, D. H., Howland, C. A., Foley, C. C., and Bennett, J. L. (1995). Barriers to reproductive health maintenance among women with physical disabilities. Journal of Women's Health, 4(5), 505-518**

Summary of Article: Nosek, Young, Rintala, Howland, Foley and Bennett (1995) conducted a study to assess the barriers to reproductive health maintenance that women with physical disabilities face. Thirty one adult women with disabilities resulting in

functional impairments were recruited through personal contact and by fliers. The ages ranged from 22 to 69.

Summary of results of study: After analysis of the data the major themes that emerged were sense of self; relationships; environmental and attitudinal barriers; emotional, physical, and sexual abuse; sexuality information, and health and sexual functioning.

A number of themes emerged from the results which were as follows:

- Themes related to participants' experiences either due to repeated hospitalizations in childhood; lack of basic knowledge about their reproductive health; abuse in medical settings which can have a lifelong traumatic impact as well as additional risk factors which these women face.
- Themes related to medical systems and practitioners like barriers to accessing health insurance; architectural and equipment barriers in medical facilities like non elevating examination table and lack of platform scales; negative and stereotypic attitudes of physicians towards women with physical disabilities; lack of direct communication; and difficulty with obtaining reliable information about contraception.

Results of this qualitative study indicate a strong influence of characteristics of medical systems and practitioners on the knowledge, beliefs, and experiences of women with physical disabilities as they strive to maintain their reproductive health. Disability status has a strong influence on internal factors that lead to reproductive health maintenance behaviors such as knowledge, beliefs, psychological factors, and medical experiences. While disability itself does not have a direct effect on environmental factors such as medical systems, professionals and equipment, it conditions the way in which medical systems and professionals respond to women. Environmental factors in turn influence internal factors.

Measurement: The study used a qualitative method of open-ended interviewing to identify primary themes and issues about the sexuality of women with disabilities. The research team developed a generalized interview guide using an iterative process based on a literature review, the researchers' own experience with disabilities, and input from women with physical disabilities in the study. Early versions of the guide suggested open ended questions that could be used to elicit the desired information, such as: "Tell us about any problems you have experienced with your sexuality. As input from the interviewees was received and analyzed, and thematic domains began to emerge, the generative questions were made slightly more specific such as: "What has been your experience in receiving services from doctors for your reproductive health?" Interviewers were instructed to let the participants lead as much as possible and to use the guide primarily as a reference to make sure key areas were covered.

- p. **Cheng, E., Myers, L., Wolf, S., Shatin, D., Cui, X. P., Ellison, G., Belin, T., and Vickery, B. (2001). Mobility impairments and the use of preventive services in women with multiple sclerosis: Observational studies. *British Medical Journal*, 323, 968-969**

Summary of Article: Cheng, Myers, Wolf, Shatin, Cui, Ellison, Belin, Vickrey (2001) conducted a study to assess how the use of preventive health services is affected by factors such as patient demographics, clinical characteristics, type of provider, and type of healthcare system. They evaluated the relation between mobility and use of preventive services in women with multiple sclerosis. Questionnaires were sent to 1164 adults with multiple sclerosis who had received outpatient care in 1993 or 1994 from one of three systems of health care (two forms of managed care and fee for service insurance). The overall response rate was 80% (930/1164) and the sample used were responses from the 713 women respondents. The mean age of the women was 47 years.

Summary of results of article: Overall rates for cervical smear tests, breast examinations, and mammography exceeded Healthy People 2000 recommendations, but rates were highest for the ambulatory group and lowest for the non-ambulatory group. Cervical smear testing was below Healthy People 2000 goals for the ambulatory with help and non-ambulatory groups. In contrast, rates for general preventive services did not differ by mobility; ambulatory patients had 5.32 times the odds of having a cervical smear test, 3.62 times the odds of having a breast examination, and 3.24 times the odds of having mammography relative to non-ambulatory patients. Older age was associated with a lower rate of cervical smear tests. Use of women's preventive health services was lower in non-ambulatory women than in fully or partially ambulatory women with multiple sclerosis. Reasons for these results have been stated as doctors may believe that such patients do not have an adequate life expectancy to warrant women's preventive screening; alternatively, patients may be reluctant to undergo screening services that are potentially uncomfortable or embarrassing. A third possibility is that the medical systems cannot easily accommodate patients with mobility impairments, who may require access to specialized equipment and extra time.

Measurement: The method of data collection used was questionnaires; however, the researchers have not provided any information about the types of questions used. Self reported rates of cervical smear testing, mammography, and breast examination, blood pressure checks, cholesterol screening, and physician estimation of health habits. Rates were assessed according to the patient's mobility level (fully ambulatory, ambulatory with help, and not ambulatory).

- q. **Whiteneck, G. G., Harrison-Felix, C. L., Mellick, D. C., Brooks, C. A., Charlifue, S. B., Gerhart, K. A. (2004). Quantifying environmental factors: A measure of physical, attitudinal, service, productivity, and policy barriers. Archives of Physical Medicine and Rehabilitation, 85, 1324135**

Summary of Article: Whiteneck, Harrison-Felix, Mellick, Brooks, Charlifue and Gerhart (2004) developed and tested a new instrument to assess environmental barriers encountered by people with and without physical disabilities by using a questionnaire format. The item development strategy was designed to ensure the content validity of the items and to reflect environmental factors as conceptualized in the current models of disability. Four separate advisory panels were convened. Panel members had a wide variety of disabilities, abilities, attitudes, philosophies, knowledge and skills. The four

panels consisted of 32 participants with expertise in 4 general arenas of disability: mobility, self-care, learning, and communication issues. Two forms of the draft were proposed with the same items but different metrics to assess environmental impact. Both forms were tested with a convenience sample of 97 subjects, 50 with disabilities and 47 without disabilities

Additional evaluation of the CHIEF was performed to determine if underlying dimensions or subscales might exist within the content of the overall scale. The evaluation was accomplished by adding the CHIEF to the Behavioral Risk Factor Surveillance System (BRFSS). The survey was administered to 2269 people using the standard BFRSS protocol.

Because the CHIEF was designed with particular interest in the environmental barriers reported by people with disabilities, test-retest reliability and subject-proxy agreement were evaluated. A convenience sample of 409 with disabilities was recruited to further test the survey's psychometric properties.

For practicality of administration purposes, a shorter version of the CHIEF was created. The goal was to select a subset of items that retained all five of the CHIEF subscales but provided a shorter, more practical form.

Summary of results of study: The main outcome measures were item development; factor structure; test-retest; subject proxy and internal consistency reliability; content, construct, and discriminant validity; and subscale and abbreviated version development. There was consistency among the environmental factors identified by the 4 separate panel members

An initial principle components factor analysis of the CHIEF's 25 item product scores resulted in 6 factors with eigenvalues over 1.0. After varimax rotation, the five factor solution (accounting for 48% of the cumulative variance) was far more interpretable. The five factors were labeled as (1) attitudes and support, (2) services and assistance, (3) physical and structural, (4) policy, (5) work and school environmental barriers.

The data showed a total CHIEF scale score ICC reliability of 0.93 and subscale ICC's from 0.77 to 0.89, indicating good reliability for the instrument and acceptable reliability for the subscales. However, participant-proxy agreement was substantially lower (total CHIEF ICC= 0.62), indicating proxies were not very accurate.

For the overall scale, reliability of the survey's internal consistency was good. It was acceptable in the disability sample; however, it was only marginal in the general population sample.

In assessing discriminant validity, it was found that all CHIEF items, all subscales, and the total score produced statistically significant differences across the impairment groups. People with disabilities reported an overall higher level of environmental barriers on all subscales and the total CHIEF score. People with severe disabilities generally scored higher on the subscales and total score.

The CHIEF showed evidence of content and construct resulting from its development strategy and psychometric assessments in samples of the general population and among people with various disabilities.

For the short form of CHIEF, correlations between CHIEF subscales and total score from the short form and long form range from 0.794 to 0.960

Measurement: For item development, a strategy was designed to help identify relevant environmental factors, draft items, and select appropriate metrics. Four advisory panels were convened and each panel brought his/her personal and professional perspectives and experiences with disability and the impact of the environment. The four 2-day meetings, each focusing on a different disability issue (mobility, self-care, learning, communication), began with a review and discussion of the role of the environmental factors in current models of disability. Participants were then asked to enumerate relevant environmental factors influencing disability outcomes. The instruments addressed environmental factors that would be appropriate for the general population as well as for persons representing the full range of possible disabilities. . The new draft identified 25 key elements of the environment including the natural environment; physical aspects of home, school, work, and community; attitudes, help and support in those settings; equipment and technology; transportation, medical, educational, and other services; and business, employment , and government policies.

The CHIEF consisted of twenty five questions which targeted various areas of access barriers for people. Some of the questions asked were related to transportation; home architecture; community access; availability of health care services and medical care; and barriers that lack of personal equipment or special adapted devices pose e.g hearing aids, eyeglasses or wheelchairs. Some of the questions included in the CHIEF were: In the past 12 months how often has the availability of healthcare services and medical care been a problem for you; and, In the past 12 months how often has the lack of personal equipment or special adapted devices been a problem for you? Examples might include hearing aids, eyeglasses or wheelchairs.

In order to evaluate test-retest reliability and subject-proxy agreement, the CHIEF was administered on all study participants. In addition, 103 out of the 409 were administered the CHIEF a second time, approximately 2 weeks after the first administration to assess test-retest reliability. Finally family members or friends of 125 participants, not included in the test-retest reliability studies, were successfully recruited and asked to complete the CHIEF as a proxy for the participant to assess participant-proxy agreement. Test-retest and subject-proxy agreement were assessed using both 1-way random effect model, single-measure interclass correlation coefficient and the percentage of cases with exact agreement between both tests.

To assess discriminant validity, differences in response patterns on the CHIEF were compared between people with and without disability in the BFRSS sample and among impairment groups in the disability sample to determine if the instrument differentiated

among groups in expected ways. Participants within the BFRSS data set were differentiated by whether or not they reported any disability.

For the shorter version of the CHIEF, several criteria were used to determine if the items should be retained on the CHIEF short form. In general, the criteria included items that had the highest correlations with the subscale and total scores, and best differentiates between people with and without disability. This analysis identified 12 items within the original 5 subscales to be retained, with 2-4 items per subscale.

IV. Conclusion

Only two of the studied mentioned above used standardized tests, the first was the study carried out by McClain, Medrano, Marcum and Schukar which used the CHIEF and the second was the study conducted by Renisow, Schorow, Bloom, Massad. In addition, these studies were also not specific to accessibility of products, much less medical products. These were often objective measurements with no structure or deliberate measurement tool. Also frequently many of the studies presented opinions of only one or two disciplines and perspectives of only a few disabilities.

However, each of the studies concluded that there is an access problem and, therefore, measured a degree of accessibility. In addition most of the studies found a significant access barrier with respect to medical equipment. Hence, there is an obvious need for an objective measurement tool to assess the degree of accessibility problem that medical equipment presents.

V. Future Research

Although a lot of research has been carried out in the area of access to health care for people with disabilities, there has been very little focus exclusively on medical instrumentation and equipment. The main focus has lain on health insurance and attitudes of healthcare practitioners towards people with disabilities. Another area of interest with respect to this topic has been architectural barriers to accessing health care. However, the barriers to healthcare access are much more varied and some may pose more of a problem than anticipated. Hence this is an area which should be further investigated because it is an area which can be remedied to improve healthcare access for people with disabilities.

One area which can pose a significant barrier to healthcare access is medical equipment and instruments. Medical instruments are often not able to be adjusted to accommodate the disabilities of people. Research in this area has also mostly focused on people with physical disabilities. People with sensory and cognitive disabilities have been largely ignored. Problems that people with sensory and cognitive disabilities face will be very different from those faced by people with physical disabilities. Research needs to be conducted in this area as well. Hence a survey that assesses each component of a task needed to use a medical instrument and which of these tasks are most difficult for people with physical, sensory as well as cognitive disabilities would be a helpful insight into this area. Further research should not only focus on patients with

disabilities. Sometimes the healthcare provider or test administrator may have a disability which impedes use of the instrument. In some instances when certain devices are self-administered the same person becomes the person with the disability as well as the device operator. All these factors should be taken into consideration when designing a tool to assess this problem. Hence the development of an assessment instrument that measures task related features as well as access barriers for different disabilities of clients as well as test administrators will be useful. In addition research may be conducted to assess exactly what instruments pose the most barriers for people with various disabilities and in what way. Thus research in this area is required and will benefit people with disabilities by improving designs of equipment.

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